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MYASTHENIA GRAVIS ESSENTIALS:

A GUIDE FOR YOUNG PATIENTS AND THEIR CAREGIVERS

A diagnosis of myasthenia gravis (MG) in a child or teenager can bring many questions and concerns – for both young people and those who care for them. MG is a rare condition that causes muscle weakness. It can affect how a child plays, eats, talks, or takes part in school and social activities.

This guide is designed to support **caregivers, including parents, guardians, and families**, in understanding MG and helping children navigate life with the condition. It also offers accessible information to help young people with MG understand what is happening in their bodies, in a way that feels reassuring and age appropriate.

This guide includes a **consultation companion** with helpful questions that you can use during doctor visits, so that everyone feels supported and prepared. You will also find a **visual cartoon** designed to help explain MG to children, who may understand better through storytelling and pictures.

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Springer Health+ IME

What is MG?

MG is a rare autoimmune condition. It means that the immune system, which normally protects the body from germs, mistakenly attacks the connection between the nerves and muscles. This makes the muscles weaker, especially with activity. The most common symptoms include:

- Drooping eyelids
- Double vision
- Trouble swallowing or chewing
- Difficulty speaking clearly
- Difficulty with facial expressions, such as smiling
- Muscle weakness in the arms or legs
- Muscle weakness that gets worse after activity and improves with rest
- Neck weakness
- Difficulty taking a full breath

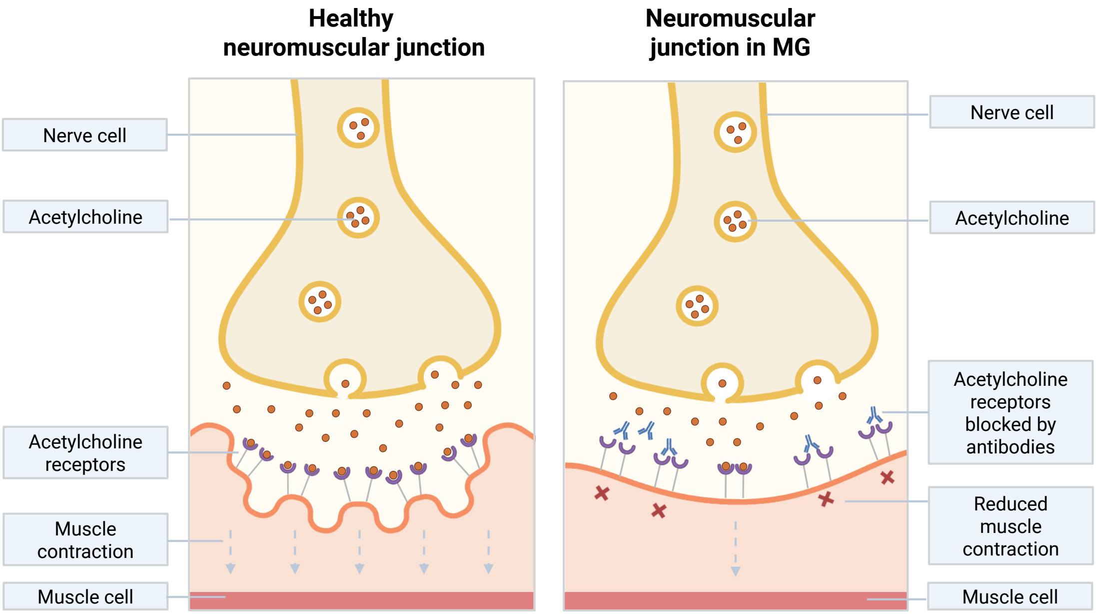
The symptoms of MG vary from person to person, which is why MG is sometimes referred to as **snowflake disease**. The symptoms can be unpredictable and changing in nature.

The two main types of MG are **generalized MG (gMG)** and **ocular MG**. gMG causes people to experience muscle weakness throughout the body, including the eyes. Ocular MG affects the eyes only.

When MG is diagnosed in children and teenagers, it is called *juvenile MG (JMG)*. This form of MG shares many symptoms with adult MG but may require different treatment and support strategies, depending on the child's age and development.

What causes MG?

MG happens when the immune system makes substances, called *antibodies*, that block or damage the connection between the nerves and muscles (called the *neuromuscular junction*). In most people with MG, these antibodies interfere with acetylcholine, a chemical that helps the muscles move.



It is not fully understood why the body makes antibodies by mistake. MG is not caused by anything a child, teenager, or parent/guardian did. It is not contagious, and it does not run in families, although there can be a genetic susceptibility in some cases.

How is JMG treated?

Starting treatment as soon as possible is important in juvenile MG to reduce symptoms, prevent disease progression, and preserve the function of the neuromuscular junction. There is no cure for MG, but treatments can significantly improve symptoms. Children and teenagers with MG should be managed by a coordinated team of healthcare professionals who work together to tailor treatment plans according to symptoms. Some treatments that you might hear of include:

Treatment	How it works
Acetylcholinesterase inhibitors	Improves communication between nerves and muscles
Corticosteroids or other immunosuppressant drugs	Reduces the immune system's attack on the body
Intravenous immunoglobulin	A treatment made from healthy antibodies collected from donated blood; used in severe cases or during flares
Plasma exchange (plasmapheresis)	A procedure that removes abnormal antibodies from the blood; used in severe cases or during flares
Thymectomy	Surgical removal of the thymus gland

In addition to medication, appropriate rest and energy management are key. Many children also benefit from physical therapy, occupational therapy, and adjustments at school to help manage their day-to-day activities while their MG is active.

Some medications, such as some antibiotics and anesthetic agents, can worsen MG. Make sure to let your child's healthcare provider know about the diagnosis of MG and consult them before starting your child on a new medication.

Being prepared for emergencies

A myasthenic crisis is a rare but serious complication of MG. It happens when the muscles that help with breathing become too weak to work properly. This can lead to difficulty breathing or respiratory failure, and it requires immediate emergency medical treatment.

Breathing problems in MG are not caused by a lack of oxygen, but by weak muscles that make it harder to move air in and out of the lungs. This is important to know because oxygen levels can still look normal in emergency rooms, even when someone is having serious trouble breathing.

Although myasthenic crisis is rare in children, it is important that families know what to look out for and have a plan in place, just in case. Although children do not need to know all the medical details, it is important that they understand when to ask for help.

Signs to watch for:

- Difficulty breathing or catching their breath
- Trouble speaking clearly due to weakness
- Severe weakness affecting all limb muscles
- Trouble holding up their head
- Difficulty swallowing their saliva

To prepare for possible emergencies, it is important to create an emergency plan:

- Discuss with your child's neurologist what to do in case of worsening symptoms
- Have an emergency care plan and emergency contacts ready
- Keep an up-to-date list of medications and all medical diagnoses
- Make a copy of all important information for school, caregivers, and to keep in your own phone or bag

Young children (ages 3–7)

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- Use simple language to explain MG: *"Your muscles get tired more quickly, and the medicine helps your body work better."*
- Use simple words to talk about symptoms (e.g., "tired legs" or "wobbly arms")
- Be aware that, along with major muscle groups tiring, smaller muscles, such as those in the fingers and toes, can tire very quickly
- Offer reassurance: your child did not cause this, and it is not their fault
- Encourage breaks between activities, even during play
  - Quiet, restful activities, such as coloring or puzzles, can be great alternatives on tiring days
- Work with teachers and caregivers to monitor symptoms and adjust schedules
- Gently remind your child that it is okay to stop or ask for help

Older children (ages 8–12)

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- Provide slightly more detail: *"Your immune system is making it harder for your muscles to get messages from your brain"*
- Use stories, comics, or kid-friendly videos to help your child understand MG and feel empowered – *check out the short cartoon at the end of this guide to help you explain MG to your child*
- Involve your child in daily care routines, such as taking medicine or recognizing signs of fatigue
- Collaborate with school staff to allow breaks, flexible physical education, and modified workloads, if needed. Encourage self-advocacy: *"It's okay to tell your teacher if you need a break"*
- Initiate conversations about how changing hormones and onset of puberty may exacerbate symptoms. Tracking and looking for patterns in symptoms can help with planning and preparing for an increase in symptom frequency or severity
- Seek psychological support if your child is struggling with the emotional impact of MG
- Once stability has been achieved with treatment, encourage children to exercise regularly according to their levels of muscle weakness and fatigue

Teenagers (ages 13+)

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- Support growing independence: help your teenager track symptoms, manage medications, and speak up in medical appointments
- Normalize emotional responses: teenagers may feel frustrated, isolated, or self-conscious about being "different"
- Encourage physical exercise and social activities that match energy levels and comfort
- Consider psychological support to help young people cope with the emotional impact of MG
- Discuss long-term planning in an age-appropriate way: school, driving, college, or relationships
- Ask your healthcare provider about any support groups for young people

Managing MG symptoms and providing support for children and teenagers

Every child with MG is different. Symptoms can vary from day to day and may be affected by activity, illness, emotions, or even the temperature. That is why it is so important to listen to your child, notice patterns, and help them learn how to understand and express how they are feeling.

It is important to recognize that people with MG are not lazy and symptoms cannot be overcome by trying harder, persistence, or will. Children and teenagers need compassion and care to help them manage MG. Below is some age-appropriate guidance for managing MG symptoms and providing support to help children of different ages feel more comfortable, confident, and supported.

Communicating with children and young people about MG

When a child or teenager learns that they have MG, questions are likely to follow. Some may ask immediately, whereas others may need time to process. It is important to welcome questions with patience, honesty, and empathy. Here are some examples of questions that young people may ask and how you can respond in an age-appropriate way:

Ages 3–7 (young children)

Children this age may not fully understand MG but will notice changes in their routine or how they feel.

Common questions might include:	How you could respond:
Why do I have [symptom]?/Why do I feel tired so much?	"Your body has something called *myasthenia gravis*, or *MG*. It makes your muscles feel tired more quickly than other kids'."
Why do I have to go to the doctor so much?	"The doctor helps your muscles feel better and makes sure your muscles are doing their best. They want to help you play and have fun."
Can I still play with my friends?	"Yes, you can! You might need to rest more often, but we'll make sure you can still have fun. And if you're feeling tired, we can find games that don't take as much energy."

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Ages 8–12 (older children)

Children in this age group may be more curious and may want to understand the condition and how it affects their life.

Common questions might include:	**How you could respond:**
What is MG exactly?	“MG is short for *myasthenia gravis*. It means that the messages from your brain don’t always get through to your muscles like they should. That makes your muscles feel weak or tired, especially after doing things like walking, talking, or playing.”
Will it ever go away?	“MG doesn’t usually go away completely, but it can get a lot better with the right treatment. Many people feel almost back to normal with their medicine and support.”
Can other people catch it from me?	“No, they can’t. MG isn’t something anyone can catch like a cold. It’s something that happens inside your own body, and it’s not anyone’s fault.”
Why do I have to take medicine every day?	“Your medicine helps your muscles work better and keeps you feeling stronger. Just like some people need glasses to see better, your medicine helps your muscles get the messages they need to move.”

Age 13+ (teenagers)

Teenagers may worry about independence, friendships, appearance, and long-term plans.

Common questions might include:	**How you could respond:**
Will I be able to drive, go to college, or have a job?	“Most teens and adults with MG do all of those things. You might need to plan your energy and manage your symptoms, but MG doesn’t have to stop you from achieving your goals.”
Are there side effects from my medication?	“Medicines for MG can have side effects, but not everyone gets them. Your doctor will explain the side effects to look out for and will also keep checking to make sure your treatment is working well for you. And if something doesn’t feel right, we can speak to the doctor.”
What happens if it gets worse?	“Sometimes MG symptoms can flare up, but your care team has a plan for that. We’ll watch closely for any changes, and if anything feels worse, we’ll go to the doctor right away. There are treatments to help during those times.”
What will my friends think?	“It’s normal to wonder about that. You don’t have to tell anyone unless you want to, but the people who care about you will want to understand. If you ever want help explaining it, we can figure it out together.”

Consultation companion

When managing MG in children and teenagers, it is important to have open and ongoing communication with your child's healthcare team. Asking questions can help you better understand treatment options, track progress, and support your child's daily well-being. As your child grows, encouraging them to participate in conversations with their doctor can help build confidence and independence.

My questions	My answers
What are the steps in the treatment process?	
What treatments are available?	
What can we expect from the treatment and what side effects are there?	
How will we know if the treatment is working, and how often should we evaluate treatment?	
How is my child's condition likely to change as they get older?	
How can I help my child manage their symptoms at home and school?	
Can you recommend any support groups or resources for families and young people living with MG?	
What signs might suggest a myasthenic crisis, and what is our plan if one happens?	
Who should be involved in my child's circle of care?	
My question 1. . .	
My question 2. . .	

Looking for support?

Connecting with others in similar situations can offer valuable advice, comfort, and a sense of community. Patient advocacy groups can provide vital information about MG, and many have platforms or support groups where you can connect with others.

Myasthenia Gravis Foundation of America

https://myasthenia.org/

European Myasthenia Gravis Association

https://www.eumga.eu/

MyAware (UK)

https://www.myaware.org/

Myasthenia Gravis Association

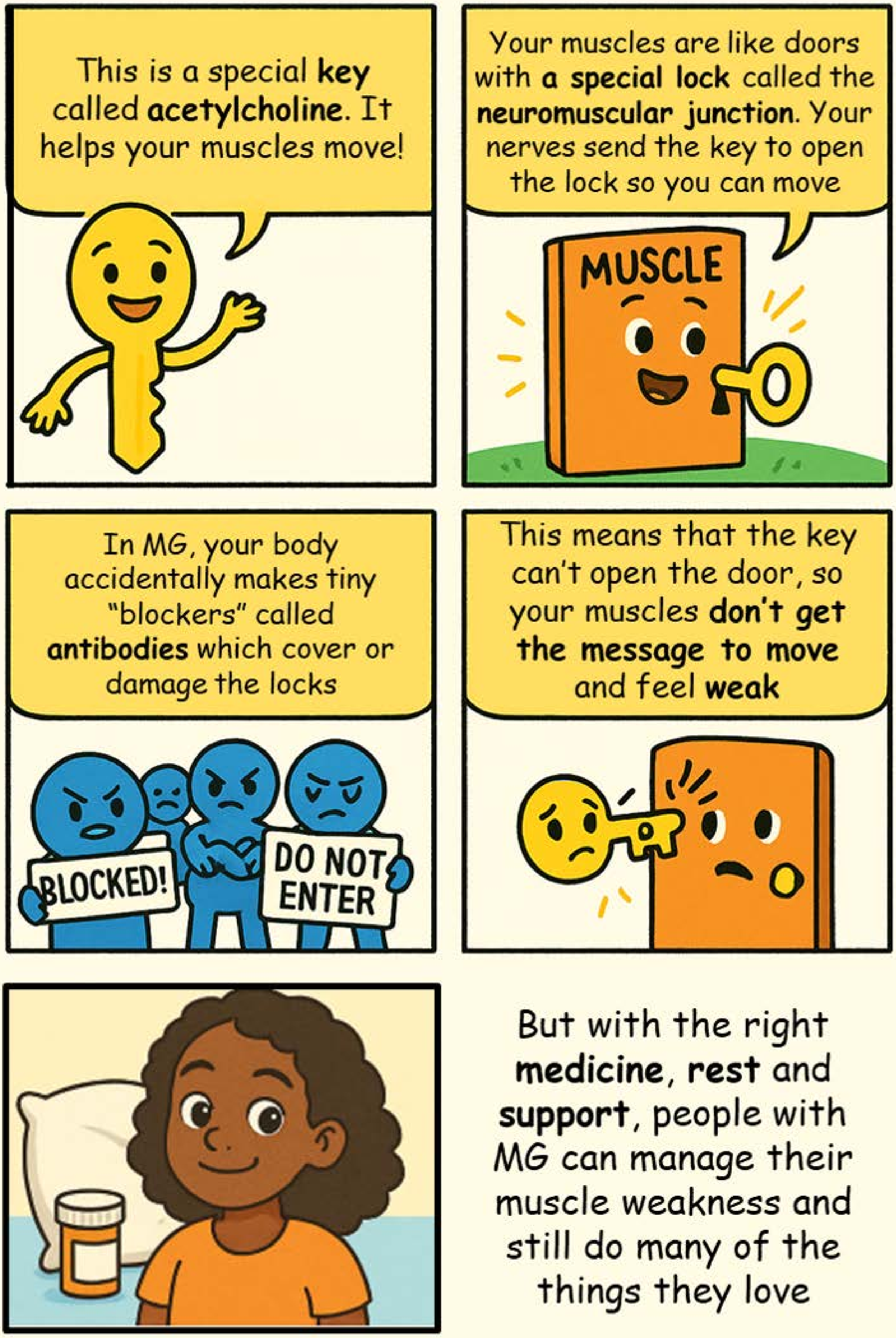
http://www.mgakc.org/

Myasthenia Gravis Society of Canada

www.mgcanada.org

Explaining MG to children

You can use this cartoon to explain MG to children, using the “lock and key” analogy:



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